Intellectual Disability Co-design

Hospitalisation Project

2016

Tracey Szanto, Manager Intellectual Disability Health Network
The ACI acknowledges the traditional owners of the land that we work on. We pay our respects to Elders past and present and extend that respect to other Aboriginal peoples present here today.
Nobody knows better how services can be improved than the people who use them and the front-line staff who provide them.

- Governance International
  http://www.govint.org/co-design/
In 2009, the NSW Department of Health supported a number of co-design projects to improve the patient and carer experience of Emergency Departments.

Many NSW health services use a co-design approach in health care improvement.

The NSW Agency for Clinical Innovation Patient Experience and Consumer Engagement team is keen to build understanding and capability across the NSW Health system in co-design thinking, practices and tools.
“people will support what they help create.”

post-it note at the front reception in Office Nomads, a coworking space in Portland, OR.
The Co-Design Hospitalisation Pilot Project is launched....

- In 2015 The PEACE Team at NSW Agency for Clinical Innovation invited the ID Health Network and MRID (a specialist ID Health pilot team) to partner with them in a Co-Design Project around Hospitalisation.
The ACI’s approach

- Learning together how co-design can be applied, adapted and promoted in the ACI and NSW Health
- Multi-pronged strategy to build capability in co-design:
  - **Coaching** from an international expert, Dr Lynne Maher, Director of Innovation and Improvement, Ko Awatea
  - Undertaking **pilot co-design project** (ACI & local ID Team)
  - Developing **co-design leaders** and a community of practice
  - Developing **resources and tools** e.g. principles, facilitation guide
Co-design approach

Co-design is an important part of a process to **capture** patient, family and staff experiences, **organise the learning** that it brings to create new understanding and insight from the perspective of the care journey and emotional journey, **come together in partnership**; patients, family and staff to review the learning, have ideas, plan and implement improvements then finally; review what difference that has made.
Methods for capturing experiences

- More generalisable
  - Surveys
  - Comment cards
  - Kiosk questions
  - SMS questions
  - In-depth interviews
  - Focus groups/panels
  - Patient stories
  - Photovoice
  - Ward rounds/observation
  - Complaints and compliments

- Less generalisable
  - Less descriptive
    - Online ratings
    - Public meetings
  - More descriptive
Case Study 2 – Tina’s Story

This graphic example of how Tina and her family experience health services (above line) and how health service staff understand Tina’s experience (below line) underpin many of the themes of this Context Report.

“\textit{We stayed with Tina in a single room in ED while she had tests and waited for a room on a ward. Her behaviour was getting more difficult to manage.}”

“\textit{It was nice we could have a single room on the ward, but no one spoke to us and we did not know what was going on. Tina was getting more difficult to manage.}”

Tina (33 yrs) has an intellectual disability. She likes cooking, bowling, art and using her computer. She is cared for fulltime by her parents and keeps to routines.

“I brought in photos and tried to tell staff that this was not the “normal” Tina.”

“We (parents) contact her Neurologist. We won’t be able to cope at home.”

Prehospitalisation

Feb 2014 Presented to ED

Admitted to Short Stay Ward

Transferred to Gastro Ward

“The staff are not familiar with people with intellectual disability and think...”

Pain, vomiting, headache and temperature. Numerous tests. Diagnosis of a bowel inflammation.

Prolonged stay as single room not available on ward. Tina has a family member

Tina pulled out her cannula and refused to eat. She is loosing weight. And her behaviour is more difficult to manage.

Tina is diagnosed with delerium. Start and discharge...”
The Co-Design Hospitalistion Project

- Participants including Carers, attended a Masterclass and subsequent coaching in co-design principles. Using participatory action research, user-centred design, learning theory and narrative-based approaches, the emotional content of healthcare hospital experiences were captured in story–telling. Issues arising were identified at a facilitated solution co-design workshop.
The solutions for improvement were then enhanced in small working groups overseen by a local steering group and supported by further coaching. These are being driven locally by the local health district with opportunities for ongoing coaching and leadership support in Co-Design offered by ACI.
Understand

What matters more than raw data is our ability to place these facts in context and deliver them with emotional impact.

- Daniel Pink, A Whole New Mind (2008)
MRID Hospitalisation Toolkit

Welcome to the MRID CoDesign Kit

The MRID CoDesign Kit provides tools to help you use the co-design principle to create relevant and sustainable health services. Here, when your resources are limited, this approach means that consumers’ priorities— their needs and wants— drive the direction of service development and delivery.

All of the tips, tools, resources and examples in the MRID CoDesign Kit have been developed directly out of many years of hands-on experience. A uniquely successful model of partnership between the Aboriginal Elders and the Aboriginal Developmental Assessment Service has proven that co-design works and has demonstrated how it can be done. The Alawa Regional Intellectual Disability Network has built on this success to show how co-design can become an integral part of delivering the highest possible standard of care to people with intellectual disability of all ages.

The MRID CoDesign Kit is for anyone wanting to improve the health and quality of life of consumers with complex health needs.

We wish you every success!
Improving the experience of hospitalisation for people with intellectual disability

Uses and Feedback

- Staff Education, Orientation, Awareness Raising and Self Management Training

  It made me cry when I realised how I might have acted.
  
  Student Nurse

  I had never thought of this as a rights issue.
  
  Allied Health Professional
I like the way we have included the consumer from the beginning and all the way through. Usually we develop something and then get their opinion.

Co-Design Team member
I like the way we listened to the clinician, the consumer and the disability staff perspectives and then we got the full picture of what was needed. Co-Design Masterclass participant.

Listening for the emotional hot spots really works!
Health Manager
Next Steps

Based on this pilot project:

- The ACI PEACE Team is currently supporting 5 co-design projects.
- The ACI PEACE Team is developing a toolkit of resources and continues to offer masterclasses and partnership projects with LHDs.
- The ID Health Network continues to develop its Hospitalisation Toolkit and work with LHDs using co-design methodology and through ID education.
- There are more and more local leaders and staff trained in and using Co-Design methodology in NSW Health.
Opportunities for further partnerships

- The ID Health Network is interested in developing partnerships with local health districts to develop models of care around hospitalisation for people with ID.
More info

- Experience-based co-design toolkit: [http://www.kingsfund.org.uk/projects/ebcd](http://www.kingsfund.org.uk/projects/ebcd)
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